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Standards of Clinical Care for People with Diabetes

Report of a CSAG Committee
and the Government Response

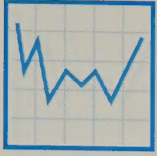
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Preface

The Clinical Standards Advisory Group was set up in 1991, under Section 62 of the NHS and Community Care Act 1990, as an independent source of expert advice to the UK Health Ministers and to the NHS on standards of clinical care for, and access to and availability of services to, NHS patients.

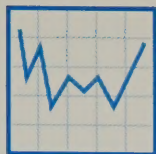
The Group's members are nominated by the medical, nursing and dental Royal Colleges and their Faculties, and include the Chairmen of the Standing Medical, Nursing and Midwifery, and Dental Advisory Committees. Its investigations are carried out throughout the UK by members and co-opted experts, supported by research units under contract. Financial support is provided by the UK Health Departments, and the secretariat is based in the Department of Health, Room LG01, Wellington House, 133/155 Waterloo Road, London SE1 8UG.

The Group's first reports, on access to and availability of specialist services, were published in July 1992. This report, on standards of care for people with diabetes, is its second; others will follow soon on urgent and emergency referrals, on maternity services and on back pain. Remits are set by the UK Health Ministers following advice from the Group.

Sir Gordon Higginson

Chairman, Clinical Standards Advisory Group
Vice-Chancellor, University of Southampton

November 1993



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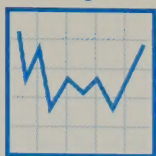
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Introduction and overview

1.1 Diabetes is a group of common chronic disorders which affects at least 2% of the population of the United Kingdom. It is particularly common in the elderly and in some ethnic minorities. Diabetes may have considerable adverse impact on lifestyle, including social aspects, through both acute problems, such as hypoglycaemia and ketoacidosis, and the potentially devastating late complications affecting a number of organs in the body. Many of these complications can be avoided or their impact lessened by proper management of the condition.

1.2 The management of diabetes takes place in primary care, in the community and in hospital and involves many professions. Its health care costs are high. At least 4% of the UK NHS budget is spent on the care of people with diabetes. Its most costly effects are the long term complications of blindness, renal failure, foot problems of neuropathic and vascular origin (sometimes leading to amputation), problems in pregnancy, and the high incidence, morbidity, and premature mortality from cardiovascular disease.

1.3 Diabetes care is, therefore, a suitable subject for an enquiry into the standards of care available in the UK. Such an enquiry has been carried out on behalf of the Clinical Standards Advisory Group at the request of the UK Health Ministers.

1.4 CSAG was given the following remit:

To advise on standards of clinical care for people with diabetes. Your investigations will include reviews of existing statements of clinical standards, of the standards specified in NHS contracts, and of arrangements for auditing the delivery of services to contracted standards, in a representative sample of NHS districts and boards.

(Secretary of State for Health, House of Commons, 16th January 1992: Hansard Volume 201 Column 627)

1.5 CSAG appointed a Committee to steer its enquiry, the membership of which is listed at Appendix 3.

1.6 This enquiry first required a consensus agreement on appropriate standards of care. The available literature includes authoritative reports from bodies such as the British Diabetic Association (BDA), the Royal College of General Practitioners, World Health Organisation, International Diabetes Federation and other international groups and bodies. From these, a Standards Document has been compiled which represents an assessment of the levels of care which should be available to all people with diabetes in the United Kingdom. Eleven districts* have been visited by a multidisciplinary group to assess how closely these standards are being met.

1.7 While the remit did not restrict the group's studies to secondary care, the visits to districts were to hospitals rather than general practices, in part for logistic reasons. The views of general

* Throughout this report, the term "districts" refers to Health Districts (in England and Wales), Health Boards (in Scotland) and Health and Social Services Boards (in Northern Ireland).

practitioners and practice nurses were sought, but no formal study of the provision of care in the community was made.

1.8 Standards of provision of care were found to be very variable. All the districts met some standards, several met the majority and one nearly all. The precise level of unmet need could not be established but is clearly considerable in many districts.

1.9 Eleven districts is far from a comprehensive sample. The figures in this report should be used in an indicative fashion rather than giving an exact proportion of the good or less good levels of provision available throughout the UK. Adequate levels of care provision were usually a consequence of the existence of well organised, adequately resourced hospital diabetes teams working in co-ordination with interested primary care teams and with effective community based resources.

1.10 Levels of care provision which did not reach the standards proposed were often the consequence of a combination of lack of adequate organisation and lack of resources devoted to diabetes care. We found no evidence that the recent NHS changes had influenced the outcome of care one way or the other but, in many cases, changes in the pattern of care consequent on these NHS changes had yet to occur.

1.11 A separate contracting process for diabetes care existed in one district only and was associated with a high standard of care. We consider it a cause for concern that only one of the localities visited disaggregated its contracts in this way and believe that the lack of specification of diabetes care, either in a separate contract or within a general medical contract, may make it difficult to improve or even maintain present standards, particularly given the shortage of resources.

1.12 Whilst our remit is specific to diabetes care, we recognise that there is a danger that an extension of the principle of the disaggregation of contracts to other similar diseases will overburden an already strained contracting process and may draw more resources into this activity than are returned in direct health care benefits.

1.13 Diabetes is an important health problem. This study has shown that standards of care can be assessed against a consensus document. Our approach would appear to be a useful model for assessing provision of care for other diseases of public health importance.

1.14 This study provides an indication of the present standards of diabetes care in the NHS. It could be used in the future to help assess changes in these standards. Many factors may affect such changes but the effects of the contracting arrangements, taking into account the resources devoted to the process itself, need further study. We hope that the present study, and any future studies that build upon it, will inform the decision-making process in the NHS, will inform all professions involved in the management and delivery of diabetes care and will lead to a better standard of care for patients with diabetes in the UK.

1.15 This report summarises the activities of CSAG's Diabetes Committee to March 1993, and makes observations based on the series of visits to districts undertaken between June 1992 and March 1993. These observations fall into three categories:

- (a) observations on standards of diabetes care provision (Chapter 3);
- (b) observations on the impact of changes in NHS organisation on the delivery of diabetes care (Chapter 4); and
- (c) an assessment of the methodology used by CSAG's Diabetes Committee. (Appendix 2).



Standards of care

2.1 CSAG's Diabetes Committee appointed a sub-group (the membership of which is listed in Appendix 3) to review nationally and internationally endorsed standards of care for people with diabetes and to unify them into a single document. This was subsequently modified and approved by CSAG's Diabetes Committee for use in its investigations. This document, "A consensus on recommendations for standards of diabetes care", appears as Appendix 1 of this report. The sources are referenced within it.

Provision of care and impact of NHS reforms

2.2 The second phase consisted of an investigation of the provision of diabetes care in selected localities in the United Kingdom so that comparisons could be made with the statements set out in the Standards Document. In addition, this phase made an assessment of the present and likely future impact of the recent NHS changes.

2.3 Between June 1992 and March 1993 twelve localities were selected. For reasons described below, it proved impossible to carry out one of these visits within this time frame. Thus, the observations in this report are based on eleven visits.

2.4 These localities were intentionally selected as being illustrative of Districts, Health Boards and Health and Social Services Boards in the United Kingdom. Thus contrasts could be made between teaching/non-teaching, inner-city/rural, those with apparently well developed diabetes services and those without. This last characteristic was assessed, in part, from the results of a survey of facilities for diabetes care funded by the British Diabetic Association and now published (William DRR and Spathis GS. Facilities in diabetic clinics in the UK: how much have they changed? *Diabetic Medicine* 1992; 9: 592-596). For the study to be truly representative would have required more resources and considerably more time.

2.5 Each team of Visitors (which varied from visit to visit) was multi-disciplinary and included representatives from diabetes medicine, dietetics, nursing, chiropody, and public health medicine. A person with diabetes was present as a member of the visiting team on most of the later visits. A general practitioner was also included in the later visits.

2.6 Prior to each visit:

- (a) the purpose of the study was explained to local purchasers, who were asked to communicate with other relevant individuals; and assurances were given that the exercise was neither a managerial nor a clinical audit; and
- (b) purchasers in the first seven localities were invited to complete a questionnaire relating to the provision of services for people with diabetes in their locality. The purpose of this was to determine whether standards of care could be successfully assessed using a questionnaire in place of a schedule of visits.

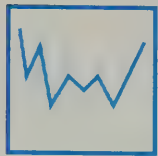
2.7 At each visit discussions were held with:

- (i) members of the purchasing team;
- (ii) members of the diabetes team in the provider unit(s); and
- (iii) representatives of provider management.

2.8 In most of the localities visited it was also possible to meet a selection of local general practitioners and practice nurses. The visit concluded with a plenary session.

2.9 The experience of the first few visits suggested the need to include a meeting with local consumers – individuals who either had diabetes themselves or cared for relatives with diabetes. Such individuals were identified by contacting the local branch of the British Diabetic Association and local Community Health Councils (or their equivalent in Scotland and Northern Ireland). By this means a group of consumers was invited to meet the visiting team on the evening prior to the visit.

2.10 In each case a draft report of the visit was compiled by one of the visiting team and circulated to the visitors and those visited for their comments which were then taken into account in drafting the final report.



Results: observations on standards of diabetes care

3.1 The structure of this section is based on the recommendations given in the summary of the consensus on recommendations for standards (Appendix 1).

3.2 All people with diabetes should be receiving continuing preventative care from a diabetes team*, aimed through education and medical interventions at normalising metabolic state according to published targets, while maintaining quality of life.

3.3 In all localities some people with diabetes were receiving a high standard of continuing care. The proportion of people with diabetes receiving care at this standard, however, varied enormously. Those places which came closest to achieving effective coverage displayed a combination of:

- (a) a well organised and adequately resourced hospital-based diabetes team with a dedicated environment for the team to work;
- (b) effective community-based services;
- (c) the presence of interested primary care teams;
- (d) effective working relationships between hospital, community-based services and primary care;
- (e) committed management (provider and purchaser) with an understanding of diabetes care;
- (f) a register of patients used for recall and audit.

3.4 Where there appeared to be a deficiency in the provision of diabetes care, major contributory factors found in more than one locality included lack of awareness of the importance of diabetes (including its impact on other services) by provider and purchaser management (one locality), poor co-ordination of hospital and community based services (four localities), and lack of the necessary information technology (five localities). These problems of understanding and co-ordination led both to poor resourcing of diabetes care and ineffective use of available resources.

3.5 The extent of provision of education for people with diabetes also varied enormously. In all but one localities, education for newly diagnosed insulin-treated patients was adequate. Access to education for newly diagnosed non-insulin-treated patients was much poorer and judged to be inadequate in seven localities. Furthermore, the provision of education services to patients in primary health care was often also a particular problem. Adequate continuing education (especially dietetic) for people with insulin and non-insulin-treated diabetes was only available in four of the eleven localities.

* A 'diabetes team' refers to a multi-disciplinary group of professionals with expertise in the care of people with diabetes. Its exact composition will vary depending on circumstances.

3.6 Funded study leave was generally granted to medical members of the hospital based diabetes team, but adequate funding for non-medically qualified professionals usually depended on the largess of pharmaceutical companies. Practice nurses, however, often had difficulty in obtaining release and/or funding for professional advancement. Specialist teams did organise regular local professional educational programmes but this was not universal. Some FHSAs were also active in this area.

3.7 All people with diabetes should have immediate and continuing access to a diabetes team (in primary or secondary care) in order to deal with changes in metabolic state, concerns over diabetes and its management, and social difficulties arising from their diabetes.

3.8 All localities recognised the importance of the team approach to the management of diabetes. However, this approach was unable to develop effectively in a number of places for the following reasons:

- (a) the absence of a consultant specifically trained in diabetes care (in two places). The poor state of diabetes care in those localities emphasised the importance of such leadership. (In one of these this deficiency has since been remedied);
- (b) a significant shortage of other team members, particularly diabetes specialist nurses (completely absent in one locality), dietitians (significant shortage in seven localities), chiropodists (nine localities), and other medical staff including a second consultant (where appropriate) (two localities). In some instances these shortages resulted in inappropriately experienced professionals being used to provide services. Dietetic and chiropody expertise was limited to crisis management in many localities;
- (c) poor team dynamics resulting from: lack of leadership (three localities); the absence of a dedicated environment in which such a team could work (four localities); the separate deployment of team members by hospital and community units and trusts (five localities).

3.9 Access to care was evidently enhanced by enthusiastic and well organised primary health care. General practitioners emphasised that this does not diminish the need for well developed hospital based services. Indeed it appeared that increased provision was required due to identification of previously unrecognised unmet need.

3.10 All people with diabetes should in addition have access to annual review for complications of diabetes and that where such a failure of preventative care is detected a suitable care plan is made to manage the complication, and that such a plan is adequately implemented.

3.11 Serious attempts had been made to implement universal annual review in ten of the eleven localities visited. In the other these activities were incorporated into routine clinic visits, not necessarily on an annual basis. However, even where serious attempts had been made to introduce full coverage, the proportion of patients included fell short of either the local target or an adequate standard.

3.12 Assurances were given that services such as vascular surgery, renal services, cardiac investigation and management, and laboratory services were available through appropriate contracts. However, it proved difficult to assess whether resources were adequate to ensure that all patients with diabetes-associated complications received appropriate care. To assess this accurately even in a small number of localities would require a detailed and costly study.

3.13 The provision of appropriate footwear, where medically indicated, was frequently not possible from local resources.

3.14 A screening programme for eye complications using local optometrists had been established in two localities and was being developed in a third, in an attempt to support the provision of diabetes care in the primary health care setting. Ophthalmology services were widely perceived to be under stress, though preferential access was given to people with urgent problems. In one locality pressures to reduce waiting times for cataract surgery were adversely affecting access to assessment and treatment of retinopathy.

3.15 People with diabetes have a major role to play not only in their own self-management, but also in the development of the service of which they are a part.

3.16 There was general recognition that patients should have a major role in their own personal care but the extent to which this actually happened varied from place to place and from individual to individual. It was not possible to gauge how much of a role some individuals played in the management of their own diabetes, because the patients and carers who were encountered during the course of these visits were probably not representative of local consumers.

3.17 Despite this, discussions with consumers provided useful insights into local issues. One example will serve to highlight differing perceptions of aspects of the service provided. In one locality the consumers interviewed were unanimous and vociferous in their criticism of waiting times in ophthalmology outpatients. They identified the problem as resulting from patients being given lengthy and unscheduled periods of laser treatment, thus delaying all subsequent appointments. The clinicians including general practitioners were equally strong and united in their praise for this aspect of the service, and considered the provision of immediate laser treatment at the clinic to be one of its great strengths.

3.18 This difference of opinion suggested, firstly that communication between professionals and users of the service was inadequate in this instance and, secondly, that the resources were not available to satisfy both the need for prompt, acute treatment and the need to reduce waiting times.

3.19 Local patient organisations existed in all but one of the places visited. In four localities they had provided considerable support and advice to the provider clinicians but in only one was there any evidence of involvement with purchasers.

3.20 Diabetes teams should be examining on at least an annual basis the success of the care delivered, through aggregation of results from metabolic outcome measures and true adverse patient outcomes.

3.21 Local attempts had been successful in identifying some areas of diabetes care in need of improvement. However, in a few localities (four) even the most basic process data were not available. Attempts were being made to collect more detailed process and outcome data in a number of localities but with variable degrees of sophistication. Some form of regular audit was taking place in seven places. There was, however, an absence of awareness amongst some purchasers of the importance of these initiatives in the identification of needs, and in the assessment of the success of the provision of care.

3.22 In three of the locations visited concerns were expressed about the ownership of data available for audit. Many providers regarded these data as their own property and were reluctant to give local purchasers access to them partly for reasons of confidentiality and partly for reasons

of “commercial sensitivity”. Purchasers stated that the details of individual patients were not required by them but that aggregated data were essential for monitoring contracts and for future purchasing decisions. However, it was freely admitted by some of the purchasers that they lacked the expertise to interpret these data.

3.23 People with diabetes in any locality should be recorded on a register, which should be updated annually to confirm that the activities described above have actually occurred.

3.24 In three localities hospital-based diabetes registers were well established and included people with diabetes attending the hospital clinic as well as those registered with some general practices (those with a particular interest in diabetes care) in the district. This allowed adequate assessment of needs but only for that proportion of the district population included in these registers. Concern was expressed that current lack of resources was putting the continued use of these registers at risk. Nowhere had a comprehensive population based register been established, there being no incentive to supply the necessary details by general practices not engaged in structured diabetes care.

3.25 Appropriate special care is offered to some groups of people with diabetes and special needs (such as pregnant women).

3.26 In all localities the special needs of people with newly diagnosed diabetes, children with diabetes, pregnant women and people with active complications were recognised. In general, special arrangements were available for children as part of the paediatric service although, in one locality, a lack of appropriate consultant cover at the local hospital meant that the focus of care for children had developed in a neighbouring town some distance away. This deficiency had long been recognised and the means were now available for it to be corrected. Special clinics for adolescents with diabetes were held in four localities.

3.27 In six localities outpatient clinics were held for pregnant women with diabetes at which both the consultant responsible for diabetes care and obstetricians were present. In other localities, however, this was not possible because of resource problems, and varying degrees of liaison between the specialities had been established in an attempt to ensure an adequate standard of care. In two localities services for pregnant women were not adequately provided.



Results: observations on impact of recent changes in NHS organisation

4.1 Many of the deficiencies in provision of diabetes care recognised during the course of these visits existed before the recent NHS changes. In three localities it was specifically mentioned that the introduction of the purchaser and provider roles had forced both (but particularly the former) to focus on local needs and the best ways of meeting them. Disappointingly, however, in five of the other localities, purchasing teams were unenthusiastic about their involvement in the provision of diabetes care. This often appeared to be because they were overwhelmed by the complexities of the contracting process.

4.2 Where problems had arisen or had been exacerbated since the introduction of the recent changes, this was usually attributed to reduced communication between the diabetes team and managers – the purchaser/provider split being taken too literally. In two localities provider clinicians stated that their input into the contracting process was being discouraged.

4.3 Dialogue in some areas was inhibited by an attitude that there should be no direct communication between providers (those with specialist expertise) and purchasing authorities. In one locality useful information gathered in diabetes registers by the providers was being retained for internal purposes only. In another, the lack of an effective diabetes team meant that this resource was not available to the purchaser.

4.4 As yet the recent changes have not had any detectable impact on the outcome of services for people with diabetes, although opinions were expressed that it might have both positive and negative influences in the near future.

4.5 The apparent lack of a clear perspective by some of the purchasing teams of the needs of people with diabetes is worrying. Most other purchasers were at an early stage in the assessment of needs within their locality. This means that the contracting process will be slow to achieve any potential it may have for improving patient care. In a few localities there was evidence that the contracting process had been beneficial, at least to the structure and process of diabetes care. The location where this was most marked was the one which had a specific contract for diabetes care.

4.6 At present, in all but one of the localities visited, diabetes services remained part of the general medical contract without detailed specification. In the district which had a separate contract for diabetes, as described above, the stimulus had come from the provider clinician. This contract currently encompasses care provided on an outpatient basis at the diabetes centre but it is planned to extend this to all hospital care provided to people with diabetes. It is recognised, however, that current hospital information systems are not adequate to identify all relevant episodes. A formal business plan for diabetes was available in one other locality.

4.7 Only three of the localities which do not have specific contracts for diabetes see their development as a priority. An advantage of such a contract was seen to be a means of retaining the integrity of the diabetes service in places where important components of care will be managed by several different providers. Thus, in districts where hospital and community services

are separate or are to be separated, complex arrangements for cross-charging will be necessary as part of the provision of medical, nursing, chiropody and dietetic services. A separate contract for diabetes services is considered to be a way to preserve the ideal of 'seamless' care.

4.8 In one locality, with a combined hospital and community trust arrangement, the complexities of a separate contract for diabetes services were considered, by the clinical provider team, to outweigh its potential benefits.

4.9 Specific quality measures for diabetes were not available within existing general contracts, although most contained statements about access to services and communication between professionals and consumers which were relevant to diabetes. Purchasers generally believed that it was up to providers to specify and monitor outcomes as a means of quality development in diabetes care.

4.10 In all localities some primary health care teams were developing diabetes care services. As a result some patients were leaving hospital care. There was, however, no evidence of any lessening in secondary unit activity. In the earlier visits, general practitioners had expressed uncertainty as to the structure of future funding of chronic disease management in general practice. In later visits, there was anxiety that the level of future financial support would be at such a low level that many practices which have recently started diabetes clinics may choose to discontinue them.

4.11 The main concerns of hospital-based providers were that general practices might set up clinics without adequate training, expertise and support staff. Some concern was expressed that fundholding practices might delay appropriate referral to the secondary sector, or fail to make use of available diagnostic services.

4.12 The members of the visiting teams regarded the consensus on recommendations on standards as an essential and appropriate basis for assessing the provision of services for people with diabetes in each locality. Some of the localities visited achieved the majority of the standards endorsed by the document. One locality achieved most of the standards set out.



We recommend:

1. that the UK Health Departments should encourage purchasers to ensure the adequate provision of diabetes services; and to adopt appropriate standards for the provision of these services within the contracting process;
2. that purchasers should establish local planning groups, involving those with expertise from both the primary and the secondary sectors, to obtain the skills and knowledge needed so that the purchasing process can achieve and maintain these standards;
3. that comprehensive diabetes registers should be developed and maintained to assist in the assessment of local needs, in ensuring comprehensive continuing care and in monitoring quality of care;
4. that purchasers should ensure that the various components of diabetes care provided by different units or trusts are specified within relevant contracts and co-ordinated through the local planning group;
5. that standards for continuing diabetes outpatient care should be specified separately within contracts in order to ensure appropriate performance and quality monitoring;
6. that, where purchasers lack the necessary expertise to implement, to an adequate level, the recommendations set out above, outside expertise should be brought in and that the Joint British Diabetic Association/Department of Health St Vincent Task Force for Diabetes should be asked to identify appropriate mechanisms for this to take place;
7. that those working in secondary care should be encouraged to continue to develop their role in supporting the optimum provision of care in the primary care sector;
8. that each local planning group should consult with one or more relevant consumer groups so that consumers can be given greater involvement in the development of their diabetes services;
9. that, as continuing education of all professionals concerned with the care of people with diabetes is essential for the maintenance of standards, the need for this should be recognised in contracts;
10. that, while many supportive services for the treatment of diabetic complications need to be strengthened and maintained, services for the surveillance and treatment of diabetic eye disease, in particular, should be improved, and consideration given to the organisation of retinal screening programmes, and enhancement of the provision and development of retinopathy treatment services (including laser photocoagulation, angiography and retinal photography);
11. that a further examination of diabetes services should be undertaken in approximately two years' time, when the effects of the contracting process should be expected to be more evident.

A consensus on recommendations for standards of diabetic care

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1. Summary

a. This document seeks to propose a standard by which the adequacy of care offered to people with diabetes may be judged. It is based on documents published by national and international expert groups listed in Table 1.

b. It is recognised that if, in a suitable sample of people with diabetes, a low incidence of adverse outcomes (including intermediate outcomes and quality of life) could be demonstrated, then no other enquiry might be necessary.

c. It is however also recognised that at present such data are not available, and that even with such data the origin of deficiencies in care resulting in adverse outcomes may not be evident.

d. We have avoided being prescriptive over the facilities and resources necessary for an adequate standard of diabetes care, recognizing that the mix of professionals and their facilities may need to vary according to local circumstances.

e. Similarly we recognise that the standard of care someone with diabetes should expect is independent of the site of care.

f. A large number of documents now exist on different aspects of standards of care in diabetes. We have attempted to derive our recommendations from the best of these consensus recommendations, and avoid novel structures.

g. The base of our recommendations are that:

All people with diabetes should be receiving continuing preventative care from a diabetes team, aimed through education and medical interventions at normalizing metabolic state according to published targets while maintaining quality of life .

All people with diabetes should have immediate and continuing access to a diabetes team (in primary or secondary care) in order to deal with changes in metabolic state, concerns over diabetes and its management, and social difficulties arising from their diabetes.

All people with diabetes should in addition have access to annual review for complications of diabetes, and that where a failure of preventative care is detected a suitable care plan is made to manage the complication, and that such a plan is adequately implemented.

People with diabetes have a major role to play not only in their own self-management, but also in the development of the service of which they are a part.

Diabetes teams should be examining on at least an annual basis the success of the care delivered, through aggregation of results from metabolic outcome measures and true adverse patient outcomes.

People with diabetes in any locality should be recorded on a register, which should be updated annually to confirm that the activities described above actually occurred.

Appropriate special care is offered to some groups of people with diabetes and special needs (such as pregnant women).

2. The Relevance of Quality in Diabetes Health Care

This document is based on fundamental principles of quality enunciated by Maxwell. These include:

Effectiveness – it is particularly important that diabetes services should be effective in reducing the impact of the potentially devastating late complications of diabetes (discussed below), and at the same time in maintaining quality of life.

Efficiency – the high prevalence of diabetes emphasises the importance of efficiency in the effective use of available resources; particularly through appropriate organization of care.

Equity – diabetes care should be equally available to all individuals with the condition. Provision of care should reflect its prevalence.

Accessibility – services should be geographically accessible, and the different components of diabetes care integrated within a locality. Information about availability of services, and walk-in and telephone access to advice, should be readily available. Accessibility should reflect acceptability to different people from different age and cultural groups.

Appropriateness – the service should be adaptable to meet individual needs for both care itself and its delivery.

Responsiveness – diabetes care services should be responsive to the cultural, humanitarian and behavioural needs of each patient, as well as to their health care needs. Those using the service should expect appropriate discussion of care plans and their progress, and of the performance of the service as whole. The service should primarily reflect the needs of the patient group, rather than those of the purchasers and providers of health care.

3. The Importance of Diabetes

3.1 Impact on health

Diabetes is a group of common chronic disorders which make a life-long impact on the health of affected people and their relatives. In the United Kingdom around 1.2% of the population have clinically diagnosed diabetes while the number of currently undiagnosed individuals is considered to increase this to 2% or more. Sub-groups within the population have a considerably higher prevalence, particularly the elderly and ethnic minorities such as those of Asian and Afro-Caribbean origin.

The prevalence of non-insulin-dependent diabetes will rise in the next decade if only because of the ageing population. There is evidence in Northern European countries of an increasing incidence of insulin-dependent diabetes in children.

The detection and treatment of Impaired Glucose Tolerance is of considerable importance in regard to its association with ischaemic heart disease and cerebrovascular disease.

Diabetes has a considerable adverse impact on lifestyle including social aspects, and through both acute problems such as hypoglycaemia and ketoacidosis, and the potentially devastating late complications affecting the eyes, kidneys and other organs.

The direct health costs of diabetes are high. At least 4% of the UK NHS budget is spent on the care of people with diabetes. Its most costly effects are the long term complications such as blindness, renal failure, foot problems of neuropathic and vascular origin (some of them leading to amputation), problems in pregnancy, and the high incidence, morbidity, and premature mortality from cardiovascular disease.

3.2 The impact of quality care

It is generally accepted that education programmes in diabetes care make a major contribution to the improvement of quality of life. Education has been shown to lead to a reduction in the incidence of hypoglycaemia and ketoacidosis. On-demand access to the diabetes service is beneficial in allowing the provision of advice on the interaction between diabetes and day-to-day living, usually at a time when it is most appropriate.

There is widespread agreement that assiduous attention to aspects of the delivery of diabetes care can reduce the impact of the adverse long-term outcomes of diabetes. In particular, long-term control of blood glucose can reduce the incidence of sight-threatening retinopathy and diabetic kidney disease. Diabetes education has been shown greatly to reduce the limb amputation rate in those at risk. Control of blood pressure, blood lipid levels and other cardiovascular risk factors are regarded as other essential aspects of diabetes care.

In the absence of a feasible strategy for primary prevention, and as diabetes is a life long condition, internationally agreed targets for diabetes (such as those of the Saint Vincent Declaration to which the UK government is a signatory) can only be achieved by improving the delivery of health care for people with diabetes.

4. Aims of CSAG's Diabetes Committee

- (i) To collate and summarize the various consensus statement available on diabetes care (listed in section 6) and, on the basis of this collation;
- (ii) To advise on the means by which standards for diabetes care can be maintained and developed within the contracting arrangements introduced into the NHS in April 1991;
- (iii) To suggest means by which providers of diabetes care can evaluate and improve the services they offer, and to supply providers and purchasers of care with a reference standard within which an adequate diabetes care service can be specified.

5. The Philosophy of Diabetes Care

5.1 Patient-centred care

Diabetes care, more than most other areas of health care, has developed its standards through active collaboration between professionals and 'consumers' (people living with diabetes – patients and carers). Its basic philosophy is that the starting point for diabetes care and its focal point must be the patient. Professional activities can only be effective and acceptable if they are planned and carried out with this in mind.

Patients now generally play the major role in managing their diabetes. It is becoming customary for targets and individual health care plans to be developed between the patient and members of the diabetes team.

5.2 The team approach

The modern practice of diabetes care requires the input of skills from different professionals within a care team. It is only with this skill-mix that the span of care encompassing education, nutrition, medical interventions, foot care, and continuing support can be combined to effect optimal outcome.

It is recognized that the functioning of a good team depends upon clear objectives, a clear sense of each other's roles, and members valuing and trusting each other.

5.3 The importance of patient education

The impact of diabetes on day-to-day living, and the central role of the patient in self management emphasize the need for multidimensional educational care. This should include delivery of knowledge, acquisition of appropriate technical skills and assistance with the development of good self-care and coping skills.

5.4 The importance of preventative care

It is recognized that a major part of continuing diabetes care should be the prevention of late complications. The maintenance of satisfactory blood glucose control, and attention to other vascular risk factors, is an important part of this.

5.5 Need for hospital admission

It is no longer regarded as necessary to admit all patients for initial or subsequent stabilization. Admission may be required principally for acute metabolic upset or foot problems with a risk of amputation. Such admissions will normally be covered by contracts for acute medical services.

5.6 Integrated care

While patients are likely to receive the majority of their continuing care from a single diabetes team (whether in primary or secondary care), it is recognized that there will usually be a need for patients to access aspects of care offered elsewhere. The organisation of diabetes care should not be such that unnecessary barriers are created between sites of health care delivery.

Family Health Services Authorities (FHSAs) and GP fundholders are also involved in commissioning diabetes services, in addition to local health authorities. Furthermore, diabetes services are provided by several providers, spanning the acute, community and primary health care sectors. In order to ensure the provision of a comprehensive and seamless local diabetes service, the specification should be drawn up jointly by all users and providers of diabetes services, District Health Authorities and FHSAs (or Health Boards/Health and Social Services Boards), and GP fundholders.

Standards of diabetes care should be equally applicable to both primary and secondary care in the NHS, the private sector, and to non-NHS organisations offering health care, including the Armed Forces medical services and the prison medical service. People with diabetes may in any case move between these sectors and the National Health Service. Without knowledge of activity within these sectors, health authorities cannot have an adequate understanding of the care provided to their population.

There is considerable variation in the mode of care provided for people with diabetes. The majority of districts do now have specialist diabetes services, although these may vary in quality. There are still some districts where patients with diabetes are followed up in general medicine clinics. Other modes of service delivery include the commissioning of special education units and district diabetes centres. The latter are considered by many to be central to the organisation of an integrated district diabetes service, providing educational and clinical support services for all patients within the locality.

Only about half of all patients with diagnosed diabetes in the UK regularly attend hospital out-patient services, the proportion being higher amongst the insulin-treated. Some of the remainder are followed up by their general practitioner (GP), but a substantial minority currently receive no systematic care. The development of GP shared-care and co-operation schemes, and the setting up of diabetes health promotion clinics, constitute two strategies which aim to improve the quality of care provided within the general practice setting. Diabetes services should recognize the need for integrated educational and clinical services to support GP-centred care.

6. Available Documents on Standards for Diabetes Care

A number of documents are now available (Table 1) addressing the issue of standards of diabetes care. Within these there is a large measure of agreement on what constitutes care of acceptable quality.

The St Vincent Declaration, the British Diabetic Association (BDA) patient charters “What diabetic care to expect” and “What professional supervision should children with diabetes and their families expect?”, and the European Patients’ Charter, are strategic statements developed jointly by consumers of care and health professionals.

Other documents address the facilities required for diabetes care, and consensus recommendations on what constitutes adequate process of diabetes care (for example the Euro-NIDDM Policy Group’s Desk Top Guide). A number of important documents and papers address specific aspects of diabetes health delivery, in regard to dietetics, chiropody, patient education, and children.

As the proper provision of diabetes care should be independent of the site of delivery of care, documents addressing the process of care in the Primary Health Care setting are also relevant to the current initiative.

Monitoring of the quality of diabetes care is addressed within some of these documents, but also specifically within the recommendations of the joint Royal College of Physicians (Research Unit)/British Diabetic Association Audit Working Group.

Table 1

Source documents on the nature of quality diabetes care:

The St Vincent Declaration. The European Patients' Charter: *Your guide to better diabetes care*

The British Diabetic Association Patients' Charter: *What diabetic care to expect*

The Euro-NIDD Policy Group Desk Top Guide *What professional supervision should children with diabetes and their families expect?* (British Diabetic Association)

Minimal educational requirements for the care of diabetes in the UK (British Diabetic Association)

Diabetes and Chiropodial care (British Diabetic Association)

Care of Diabetics with Renal Failure (British Diabetic Association)

Dietary Recommendations for People with Diabetes: an Update for the 1990's (British Diabetic Association)

Assuring Quality in Diabetes Nursing. Royal College of Nursing Diabetes Forum (in preparation)

Standards of Practice (in Dietetics) (Draft) (British Dietetic Association)

A proposal for the Continuing Audit of Diabetes Services (Royal College of Physicians (Research Unit)/British Diabetic Association Audit Working Group)

Clinical Practice Recommendations (American Diabetes Association)

Recommendations for Diabetes Health Promotion Clinics (East Anglian RHA)

Diabetes Information Folder (Royal College of General Practitioners)

Report of the Working Group on the Management of Diabetes (Scotland)

The Development of a Specification for Diabetes Services (Cambridge HA)

Model Specification for Diabetes Services (East Anglian RHA)

British Diabetic Association National Survey of Diabetes Services

Epidemiologically-based Needs Assessment - Diabetes Mellitus (NHS Management Executive)

British Diabetic Association National Survey of Diabetes Care 1990 (in preparation)

References are given in full in section 10

7. Internal Monitoring of the Quality of Care

Neither the quality nor the efficiency of care is likely to be optimal in the absence of a system of internal audit. This is particularly true of a condition such as diabetes with high prevalence in which appropriate clinical activities are not in general rewarded by immediate changes in

patient symptoms and well-being, but rather by reduction in the frequency or a diminution in the intensity of the potentially devastating late outcomes.

Any approach to quality assurance should be directed to quality in health care, as well as to quality in health care delivery.

Assessments of quality of health care in diabetes will in general only be interpretable by professionals with a special interest in this area of medicine. Such audit should be undertaken regularly and at least annually. Services should interpret results in accordance with the targets set by consensus groups, and in the light of comparative results becoming available from early national and international audit initiatives. Purchasers of health care will need to obtain specialist advice in assimilating the results of any such audit.

Means of assessing the quality of diabetes health care are currently being explored. It is suggested that they should include some of the following:

- a. Aggregated data to show service performance on intermediate outcome measures (glycated haemoglobin, cholesterol, triglyceride, body mass index) both in terms of process (percent in year checked) and result (percent in categories recommended by consensus guidelines).
- b. Aggregated data to show service performance on risk factor control, namely blood pressure and smoking both in terms of process (percent in year checked) and result (percent in categories recommended by published consensus guidelines).
- c. Percentage of patients with markers of adverse outcomes including microalbuminuria, retinopathy, asymptomatic neuropathy, absent foot pulses, rising serum creatinine.
- d. The number of amputations performed per thousand patients under care, the number of patients newly registered blind (or with vision deteriorating to worse than 6/36), the number requiring renal transplantation or dialysis, and the number suffering myocardial infarction, or stroke, within the last 12 month review period.
- e. The percentage of patients with diabetes-associated symptoms, including angina, claudication, neuropathic pains, and impotence.
- f. The number of medical interventions per thousand patients under care required for hypoglycaemia or for hyperglycaemic emergencies.
- g. The median number of days of loss of ability to perform normal daily activities within the last 12 months for the patient group under care.
- h. Percentage of patients meeting the minimum standard of non-crisis dietetic review yearly, non-crisis educational review yearly, and (for those with neuropathy and/or peripheral vascular disease and/or foot deformity or skin problems) the percentage under regular chiropody review.

It is recognized that services will wish to monitor aspects of the adequacy of educational review, but as yet there is little consensus over appropriate measures. Assessments might be made of items such as the percentage of patients performing self-monitoring to an appropriate standard, percentage membership of national patient organisations, carriage of diabetes identification, use of appropriate footwear, and knowledge questionnaire scores.

There is at present no suitable quality of life or health status measure for everyday use in people with diabetes. Global healthcare satisfaction measures largely reflect expectation, and are not in general recommended. An individual approach to this area may at present be more satisfactory.

Services should also give some attention to the quality of health care delivery, including waiting times, patient satisfaction with health care delivery, provision of information, and continuity of care.

Important measures of comprehensive diabetes health care provision in a locality will include the percentage of persons with diabetes diagnosed and registered compared to expected, and the percentage of persons with diabetes known to be receiving planned follow-up (both preventative care and annual complication screening).

Health professionals from different disciplines should be aware of, and be responding to, documents from their national associations, including the British Dietetic Association's Standards of Practice, and the Royal College of Nursing's (Diabetes Forum) statement, *Assuring Quality in Diabetes Nursing*.

8. Core Aspects of the Provision of Care

The following are regarded as foundations of an adequate standard of diabetes care:

8.1 Education and continuing education of professionals

All members of any team caring for diabetes patients must be appropriately qualified within their area of expertise. They should be expected to attend several days of continuing education in diabetes care every year. Such education may be specific to their interest (dietetic, teaching methods) or more general (diabetes conferences). Primary health care teams and hospital services should release personnel and provide appropriate funding for such activities. A record of such attendance should be kept by any diabetes team.

It is recognized that some personnel newly appointed to diabetes teams, or in a new service, may not have the experience to operate independently. During further training such personnel should remain under appropriate supervision.

Within the diabetes team members should share expertise and skills. Formal team meetings should be the basis of continuing in-service education and review of the quality of the diabetes service. They should also provide the forum for development of service protocols and quality assurance initiatives.

Every patient should expect that their care teams should include members with the following skills:

1. Educational skills to impart knowledge and self-care skills and enhance motivation;
2. Clinical and diagnostic skills, including skills in the examination and assessment of the feet and eyes and in the assessment of symptomatic neuropathy, hypoglycaemia, and impotence;
3. An understanding of the aspects of care underpinning diabetes management including appropriate nutrition;
4. Treatment skills including a knowledge of the treatments available outside his/her own team;
5. Administrative skills including those required for managing the diabetes team, maintaining the diabetes register, and performing or obtaining a review of service performance.

It is often helpful for personnel to be members of their appropriate professional and diabetes associations.

Specialist diabetes teams have an important role in the organization of continuing education for all health care professionals who come into contact with people with diabetes.

8.2. Guidelines for care

Every diabetes service in whatever site should provide a set of guidelines for care. These should be discussed among all diabetes service providers together with purchasers of care. Such a protocol of care should include:

1. A statement of the processes of care to be followed after diagnosis including education programmes;
2. The use of appropriate forms to prompt action and record aspects of diabetes care;
3. A statement of the targets to be set for diabetic patients with reasonable life expectancy including those for intermediate outcome measures;
4. A protocol for regular preventative review to achieve these targets so far as is possible;
5. A protocol for annual review including educational and dietetic review and review for adverse outcomes, markers of adverse outcomes, and cardiovascular risk factors;
6. Guidelines for the management of dyslipidaemia, hypertension, and foot problems;
7. Guidelines for diagnosis, self-monitoring techniques, nutritional recommendations, injection techniques, introduction of intervention therapy;
8. Protocols for co-operation with other teams, and for communication of relevant information to patients and professionals.

8.3 Diabetes registers and organization of records

It is recognized that diabetes care requires a number of health-care processes to be performed recurrently on a regular basis in a large number of people. Without some type of organized record, efficient and complete care is very unlikely.

Diabetes registers have been developed in a number of localities, and have a useful role to play in improving diabetes care in those sites. The provision of a register of all patients with diabetes within the District can facilitate the support of both hospital-based and general practitioner care systems and can ensure adequate supervision and follow-up for all patients. Registers can be based on a single site of care or cover a wider area.

Purchasers of care should encourage and support the development and maintenance of registers of all people with diabetes, which as a minimum should show the service (doctor) responsible for the diabetes care of that patient, year of diagnosis, and the date of last annual review for complications screening. Locality-based registers are most useful in assessing whether diabetes care is reaching all those with the condition, but service-based registers are essential in assessing quality of care. Locality-based registers are essential for identifying rates of default from care and deaths.

8.4 Chiropody

a. Access should be available to a state registered chiropodist at 2-month intervals or less for any person with diabetes who has significant:

- peripheral neuropathy;
- peripheral vascular disease;
- foot deformity or poor skin condition;
- eyesight or physical problems preventing adequate self-care.

b. Time should be available during such access for education in foot-care and its importance, as well as for foot assessment and management.

c. Where active foot lesions are present access should be available to a chiropodist as frequently as required, which may be weekly or rarely more often.

d. Such a chiropodist should be in regular contact with other members of the diabetes team caring for the patient, and should have access to appropriate educational literature for patients.

e. Foot services should have access to appropriate support services including shoe fitters and plaster technicians.

Advice on foot care is an integral part of any diabetes education programme, and should be specified within education protocols.

8.5 Dietetics

In each locality there should be an identified senior dietitian with a special interest in or knowledge of diabetes care to take special responsibility for organization and co-ordination of dietetic services in diabetes care and of dietetic education for all relevant health professionals.

While many members of the diabetes team will give nutritional advice from time to time, all newly diagnosed patients should be offered consultation with a registered dietitian within 4 weeks of diagnosis, and the opportunity of at least one further review.

Non-crisis dietetic review should be available annually to every person with diabetes. Provision should be made for more frequent review of patients with special problems including those with dyslipidaemia, perceived poor practice or knowledge, pregnancy (and pre-pregnancy), renal disease, obesity (for a period), and hypertension.

Registered dietitians should have a major role as members of the local diabetes team, in local diabetes education initiatives, and in observing and modifying the practices of other professionals involved in giving nutritional advice.

Appropriate practice requires appropriate resources including educational literature, other teaching aids, and replica foods.

8.6 Communication and information

A diabetes service report is a useful document on which to base assessment of quality. In addition to containing the results of internal audit (discussed in section 7), it should contain information on changes made in organization and practice to improve care. Such a report might be required by purchasers of care.

People with diabetes should expect that the results of annual reviews and regular reviews should be communicated to them either in direct discussion or, in written form within 3 months. The individual care plan or modifications to it should be outlined at the same time.

All diabetes services should provide each patient and relative in continuing care with an access information leaflet, detailing routes of contact to individuals within the diabetes team, and in particular means of obtaining advice in emergencies and out of hours. Such leaflets should name the members of the diabetes team.

Communication between health care teams involved in a patient's care should occur with any significant change in assessment of their health status, in the care plan, or in management. Where diabetes care is shared between sites provision should be made for a co-operation card detailing the main data fields of regular and annual review.

9. The Elements of Planned Diabetes Care

9.1 Case ascertainment and diagnosis

Current opinion favours active case finding and screening of selected groups, rather than screening the whole population. Protocols should specify the need for particular attention to those people with major vessel disease of any kind, to those with a family history of diabetes or arterial disease, to people from groups with a high prevalence of diabetes, and to the elderly. Pregnant women are a special case (see below).

Diagnosis may only be confirmed by laboratory-based blood glucose estimation. An appropriate protocol for diagnosis including WHO guidelines should be available in every diabetes service.

An oral glucose tolerance test is only occasionally required for the diagnosis of diabetes.

9.2. Care of the newly diagnosed

Initial assessment

The initial assessment should confirm the diagnosis of diabetes, identify possible contributory illness, identify concurrent illness which might interact with diabetes management, identify any vascular disease or complications of diabetes which may already be present, assess the presence of other risk factors for vascular disease, provide an educational and emotional assessment of how an individual (and relatives) might handle diabetes self-management, and identify social factors likely to interact with diabetes or its management.

Time should be available for this assessment to be provided by senior members of the diabetes team.

Full medical examination is also required in order to identify possible contributory illness, identify concurrent illness which might interact with diabetes management, and identify any vascular disease or complications of diabetes which may already be present.

Laboratory measurements for the same purposes, and to provide a baseline for future care may include glycated haemoglobin, serum lipid profile, serum creatinine, liver function tests, urinary

albumin, and electrocardiogram. Some patients will require estimation of serum c-peptide, islet cell antibodies, thyroid function tests, autoantibody screen, and chest x-ray.

Occasional patients may require more detailed investigation for other possible problems identified on initial assessment. In-patient care is only required for the clinically unwell.

Information, education and social management

At initial assessment time should be available for a full explanation of the nature of diabetes, its possible impact on health, and the help that will be given to prevent or reduce that impact. That opportunity for discussion of concerns and questions is of major importance. A care plan should be agreed and explained, and should include educational goals. The role of different members of the diabetes team should be introduced.

Every newly diagnosed patient should be provided with a copy of the British Diabetic Association's leaflet, *What diabetes care to expect*, or the European Patients' Charter, or a locally derived equivalent.

Education should be provided on an individual basis or in groups (according to individual requirement and type of diabetes) to include: the nature of diabetes; the reasons for maintaining good metabolic control; the roles of eating, activity, and treatments in achieving good control, self-monitoring skills and interpretation of results; dealing with hypo- and hyper-glycaemia; aspects of self-care including self-management during concurrent illness and appropriate foot-care; the complications of diabetes; dealing with life-style variations; dealing with social difficulties including driving, insurance, employment, and holidays; the role of patient organisations, and relief from prescriptions charges; insulin injection technique and dose adjustment (where appropriate).

Appropriate literature and facilities are required to support diabetes education.

Continuing care after diagnosis

Review by the diabetes team in the months after diagnosis will need to be more frequent than for continuing care (see below), until management and educational targets are met, or the prospects and possibilities for further improvement in metabolic outcomes and vascular risk factors are exhausted.

9.3 Continuing care of diabetes

Continuing care of people with diabetes has two major parts:

- (a) **Routine review** to prevent and manage diabetes-associated complications, and to optimize quality of life;
- (b) **Formal Annual** review to detect diabetes-associated complications.

These elements are combined in some services, but this requires a higher level of organisation to ensure performance.

(a) **Routine Review**

Education and social management

1. All people with diabetes should have the opportunity of continuing discussion about problems of maintaining optimum control of blood glucose and lipid levels in their home and work environment, and about concerns over diabetes complications.
2. All people with diabetes should have the opportunity to seek advice at short notice or at regular review where diabetes is causing difficulties with their life style including driving, employment/education, travel, and recreation.
3. All people with diabetes should have the opportunity for further diabetes-specific education where annual or routine review identifies difficulties or deficiencies in the knowledge, skills, or motivation necessary to maintain adequate control of diabetes and satisfactory quality of life.

Medical management

1. Measurement of glycated haemoglobin should be available and performed on a routine basis, which may be annually if the result is consistently within mean + 4SD of the normal range in the diet- or tablet-treated patient, at least twice-yearly in all insulin-treated patients, or more often in patients with sub-optimal and especially changing metabolic control. Fasting blood glucose estimation may fulfil the same function in the diet- or tablet-treated patient if deemed appropriate by the clinician, if acceptable to the patient, and if audited against glycated haemoglobin estimation at least annually. Fructosamine results are also acceptable for regular review in most patients if audited annually in each individual against glycated haemoglobin.
2. The result of any such test should be discussed with the patient in terms of microvascular risk and the relation of the result to self-monitored results. Medical review of the result should be made with a view to assessment of the need for change in therapy or further education advice on life-style or dietetic information, and the result communicated to other professional teams involved in the patient's care.
3. Review of patient self-monitored urine or blood results should be made at every patient contact, and their meaning and importance discussed, with particular regard to facilitating self-management. Attention should be given to alteration of the care plan to improve life style and metabolic control where appropriate.
4. Measurement of serum cholesterol and triglyceride levels should be made and acted upon on a similar basis.

Risk factors

1. Measurement of sitting blood pressure should similarly be made on a regular basis, particularly if hypertension microalbuminuria, or renal impairment is present. The result should be given to the patient, with interpretation as to its significance in terms of renal/stroke risk and the need for management if abnormal. A patient-held blood pressure record card should be completed for those with hypertension.

2. Management of hypertension where indicated should be by drugs not known to disturb carbohydrate or lipid metabolism, which must therefore be available on the local formulary. Anti-hypertensive preparations may be prescribed at relatively low levels of blood pressure in those with evidence of diabetic renal damage, to inhibit its progression.
3. Discussion of the role of smoking in the patient's life-style, and the health consequences of it, should be made at each review visit in those still smoking. Education resources on stopping smoking should be available.

Complications

1. Complications of diabetes should be the subject of formal screening in every identified person with diabetes annually (see below). Where any such problem is identified it should receive appropriate management by the diabetes team on a regular basis. Thus every patient record should be organised so that identification of whether a patient has a complication related to diabetes is readily available, as should be the date of the last assessment.
2. Any patient with retinopathy not under the care of an ophthalmologist should have retinal assessment 6-monthly or more frequently if needed, unless a doctor decides that this is unnecessary. Where a doctor with no special experience in retinal assessment is concerned about retinal appearance or a change in visual acuity then the patient should be reviewed within a month of referral by a doctor (diabetologist or ophthalmologist) with special expertise.
3. Any patient with identified foot problems or peripheral neuropathy or peripheral vascular disease should have access to intensified educational and treatment input from the diabetes team including a state registered chiropodist.
4. Any patient with early renal disease including microalbuminuria should receive intensified attention to blood pressure, blood glucose, and blood lipid control.
5. Any patient with major vessel disease should receive intensified attention to blood lipid control.
6. Any patient with a symptomatic problem (including painful neuropathy, impotence, angina) should receive appropriate advice on reducing the symptoms and prevention of progression of the underlying condition.

Medical review

1. Every patient under the continuing care of a specialist or general practitioner should expect personal review by the senior doctor responsible for their care at least once in any 12-month period. This review may be combined with the formal annual review (see below). It should include:
 - a. A check that all necessary health care checks including annual review have been performed;
 - b. A check that appropriate action including appropriate referrals has occurred in respect of identified adverse outcomes or early markers thereof;

- c. Confirmation that appropriate action has been taken to improve intermediate outcome measures (glycated haemoglobin and lipids) as far as is appropriate in any individual;
- d. Discussion of the above results and plans with the patient;
- e. Time for the patient to make his/her concerns and worries known, and for these to be addressed, or be made the subject of a plan for future care improvement;
- f. Review of the results of consultations with chiropodists, diabetes specialist nurses, and dietitians.

2. If it is the case that:

- a. Intermediate outcome measures remain unsatisfactory according to international guidelines (unless, after repeated review, all appropriate intervention measures are exhausted); or

- b. adverse outcomes, markers of adverse outcomes, or risk factors are in need of continuing management; or

- c. the patient has concerns for which he/she requests continuing input from a doctor; then the patient should expect to see a doctor in addition to other members of the care team repeatedly throughout the year at an interval determined by the need, so that the care plan can be effectively implemented. The doctor (in primary health care or hospital) seen at these times should have a special interest in diabetes care, or immediate access at the time to a doctor with such a special interest, and the process should be organized to ensure care continuity when more than one doctor is involved in the diabetes service.

Any patient lost to follow-up to a hospital diabetes service should be notified to the appropriate primary health care team after efforts to restore contact, and any such patient or any patient failing diabetes appointments in primary health care should be contacted by his/her practice.

(b) **Formal Annual Review**

In addition to routine review aimed at prevention of complications and improvement in quality of life, all people with diabetes should be offered a formal Annual Review to include:

- 1. Screening and assessment of adverse outcomes including assessment of:
 - visual acuity;
 - cataracts;
 - foot ulceration, amputation;
 - symptomatic neuropathy, impotence, claudication;
 - angina and occurrence of myocardial infarction;
- 2. Assessment of markers of adverse outcomes including:
 - microalbuminuria, proteinuria, serum creatinine;
 - retinal status (by ophthalmoscopy through dilated pupils or retinal photography or formal optician review);
 - peripheral neuropathy;
 - abnormal injection sites;
 - foot deformities and skin condition, peripheral pulses;
- 3. Assessment of cardiovascular risk factors including smoking and blood pressure;

4. Assessment of intermediate outcome measures including:
glycated haemoglobin;
serum cholesterol and triglycerides;
body weight as body mass index.
5. Review of knowledge of diabetes and patient desire for further information about diabetes and indicators of self care and home monitoring of blood glucose;
6. Review of foot care;
7. Review of understanding of dietary principles of diabetes self care and patient requirements for further information on these topics.

9.4 Laboratory investigations

All laboratory measurements discussed above should be performed if possible in a CPA accredited laboratory, or if this is not yet available locally a laboratory with proper procedures for quality control and quality assessment for all relevant assays.

In the case of some less complex tests, and with the exception of diagnostic blood glucose estimation, an appropriately organised clinical user laboratory may be appropriate. This should be subject to relevantly quality control and quality assessment, and should be audited against a CPA accredited laboratory when available locally.

9.5 Diabetes management in special situations

1. Referral to other specialist services for diabetes complications

Except where special factors operate (patient choice, malignancy) each patient with diabetes should be referred to specialist services using the same criteria (but sometimes at an earlier stage) as for somebody without diabetes. Such referrals shall include when appropriate:

- a. Cardiological services (including angiography, bypass grafting, angioplasty);
- b. Vascular services (including grafting, angioplasty);
- c. Nephrological services (including dialysis, early renal transplantation);
- d. Andrology services where not offered within diabetes services (including vascular assessment, provision of erection aids, implants).
- e. Ophthalmological Services:

Where a doctor believes retinal appearance suggests the possibility of sight-threatening retinopathy, or where change in visual acuity suggests the possibility of macular disease, the patient should be reviewed within one month of referral by an ophthalmologist with access to facilities for angiography and photocoagulation;

Where non-sight-threatening change or cataract is judged to require ophthalmological referral then the patient should be seen according to local ophthalmological contracts.

2. Pregnancy and pre-pregnancy counselling
 - a. Every woman of child-bearing age who might become pregnant should be offered counselling and advice annually on the significance of diabetes in pregnancy.

- b. Every woman identified as considering pregnancy should be offered intensification of diabetes management including education, dietary, and medical advice.
 - c. When pregnant every woman with diabetes should be offered frequent medical consultation, fortnightly or as indicated, with intensification of diabetes management as above, monitoring of blood glucose control, and recurrent assessment for progression of complications.
 - d. Diabetes services caring for pregnant women should make special arrangements with obstetric services for the joint review of such women.
 - e. A record should be kept of the maternal and fetal outcome of every pregnancy in a mother with diabetes. Such data should be aggregated for internal audit and made available to purchasers of health care on request.
3. Children and young people

Children and adolescents have distinct requirements for diabetes care. This document does not seek to define in detail a standard for adequate paediatric diabetes care.

It is generally agreed that in this group diabetes care should be provided by specialist paediatric teams. In the younger groups in particular management must take account of the whole family. It is generally found useful to have specialist psychological advice available within the paediatric diabetes team.

Considerable damage can occur to children with diabetes as a result of the difficulties of obtaining good metabolic control in youngsters. Paediatric diabetes services therefore have to devote considerable resources to obtain adequate care.

Annual screening for complications is necessary from puberty, but has a useful educational role when performed earlier.

4. Elderly people

Diabetes has its highest prevalence in the elderly. Where the patient's problems are mainly diabetes-related (diabetes and vascular), appropriate follow-up by the diabetes team is preferred.

However, the follow-up of patients with multiple problems is best included within contracts for geriatric care. In these circumstances support will need to be available from the diabetes team for the geriatric services.

Metabolic targets for diabetes care should be modified on the basis of life expectancy, and not age.

5. The hospitalized patient

The majority of in-patient episodes of people with diabetes are for unrelated health problems. However diabetes often complicates their management through disturbed metabolism, excess infection rates, and thrombotic and vascular problems. Diabetes professionals should be available to advise on diabetes management of such patients, and this may need to be intensive, especially peri-operatively. Special assessment may be necessary pre-operatively (for example fundoscopy before administration of heparin for vascular procedures).

In-patient and peri-operative blood glucose control should be a subject for audit.

Reagent strip glucose monitoring is an essential aspect of in-patient diabetes care. Appropriate training of nursing staff and a quality assurance scheme should be provided.

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Appendix 2 | Assessment of methodology

1. It proved possible to review the published standards and, because of the extent of agreement between them, to compile a core document (see Appendix 1) initially for use by the Visitors.
2. The extent of co-operation from the localities in arranging visits was welcome but, in some cases, it was apparent that difficulties were encountered in bringing together all relevant groups in the time given. One visit was cancelled at short notice by the purchasers.
3. During the visits themselves the extent of free discussion with purchasers and providers was encouraging and it appeared to the Visitors that those being visited frequently benefited from the opportunity to review and discuss local diabetes care provision.
4. The Standards Document was used as the background against which the provision of services in each locality was assessed. The document was not used as a formal checklist as it was considered that this would have created barriers to the spontaneity of the discussions. However, an informal checklist was found to be useful in ensuring coverage of relevant issues.
5. The duration of the visits (9.00 am to 3.00 am) proved generally adequate to discuss relevant issues with all members of purchaser and provider teams. However, the following organisational issues were identified:
 - a. members of one clinical team felt inhibited by the presence of their managers;
 - b. there was inadequate time on the day of the visit for the Visitors to review their findings amongst themselves;
 - c. partly because of (b) above, the best use was not made of the final plenary sessions;
 - d. additional time was required to meet the consumer group.
6. It was generally agreed that the visits provided essential insights which were not generated from the questionnaire which was, therefore, abandoned after seven visits.
7. The question of participation in the visits by people affected by diabetes (including carers) was raised early on in the sequence of visits. There was general agreement that such people should be involved and, as a result, in all subsequent localities, Community Health Councils and local British Diabetic Association branches were contacted and asked to suggest individuals who could be invited to a meeting with the visitors held on the evening before the visit itself.
8. The BDA branches responded more effectively than the CHCs. In all but one visit a group of local consumers was identified and provided useful insights into the local service. It was requested that they should represent a spectrum covering insulin-treated, adults and children as well as patients looking to the hospital team as the main focus of care and who were being followed up in general practice. Usually, however, those individuals identified were biased towards those who were predominantly insulin-treated hospital attenders.
9. It was useful to have, as a member of the visiting team, a person with diabetes.

10. It was recognised that the general practitioners and practice nurses who met the Visitors tended to have a special interest in diabetes care. However, this part of the visit was felt to be illuminating when a critical mass (in both senses of the term) of general practitioners and practice nurses could be assembled. No entirely satisfactory solution to the problem of selecting primary care teams was found although, for later visits, the logistic problems were eased by contacting Local Medical Committees for nominees.

Appendix 3 | Membership and acknowledgements

Members of CSAG's Diabetes Committee:

Ms M Aitken – then Chief Area Nursing Officer, Greater Glasgow Health Board
Ms FJ Brown – Diabetes Nurse Specialist, Glasgow
Ms S Cradock – Diabetes Nurse Specialist, Portsmouth
Prof PD Home – Consultant Physician and Professor of Diabetes Medicine, University of Newcastle upon Tyne
Dr AP Hopkins – Director, Research Unit, Royal College of Physicians of London
Dr JM O'Brien (Chairman to February 1993) – Director of Public Health, East Anglian Regional Health Authority
Dr C Waine – General Practitioner, Bishop Auckland
Professor Sir Dillwyn Williams (Chairman from February 1993) – Professor of Histopathology, University of Cambridge
Prof DRR Williams – then University Lecturer/Consultant in Public Health Medicine, Institute of Public Health, Cambridge
Dr L Williams – then Director of Public Health and Chief Administrative Medical Officer, Clwyd; and a person with insulin-dependent diabetes.

Members of the sub group to review standards:

Ms FJ Brown, Ms S Cradock, Prof PD Home, Prof DRR Williams. Co-opted members – Dr M Guy (Consultant in Public Health Medicine, North West Thames Regional Health Authority) and Ms E McGill (Specialist Dietitian, Roehampton).

CSAG's Diabetes Committee appreciated the helpful advice of Mr J Apfel, President of the European Union Of Diabetics.

Many individuals were involved in the organisation of the visits which form the basis of this report and in the discussions which took place during these visits. Their assistance is gratefully acknowledged. The following people, in addition to members of CSAG's - Diabetes Committee and the Standards Document Sub Group, gave up their time to take part in the visits – Dr William Alexander, Dr Leslie Bissett, Mr David Clements, Ms Sue Durrant, Dr William Kelly, Dr David Large, Mr Alistair McInnes and Dr Peter Tasker. Mrs Marianne Quinn played a particularly important part in the organisation of the visits and in the compilation of this report. Her assistance is gratefully acknowledged.

Government Response to CSAG Report on Clinical Care for People with Diabetes

1. The report of the Clinical Standards Advisory Group (CSAG) on Standards of Clinical Care for People with Diabetes is being published simultaneously with this Government Response.
2. This response is written to follow the same structure as the CSAG report and comments on the report's observations on standards of diabetes care provision and on the impact of changes in NHS organisation, and on the report's recommendations.
3. It is relevant to note four developments which will bear on the use of the resources available for the further development and provision of services for people for diabetes. These are the St Vincent Taskforce, the Chronic Disease Management Programme, the issue of clinical guidelines and publication of a health care needs assessment review for diabetes.

The St Vincent Joint Task Force for Diabetes

4. In 1980 and 1985, the World Health Organisation (WHO) published Expert Committee Reports on Diabetes Mellitus, recognising the large and growing importance of the disease and the opportunities to reduce its impact. A direct outcome of concern that action should be taken was the initiative of the European Region of WHO to meet in St Vincent, Italy, in October 1989. This meeting was attended by about 400 representatives of diabetes patient associations, government Health Departments and health professionals from 32 European countries. Its conclusions and recommendations were summarised in what has become known as the St Vincent Declaration (and which is included in CSAG's list of source documents). A copy is appended.
5. The joint Department of Health/British Diabetic Association Taskforce (referred to on page 13 of the CSAG report) was established in the summer of 1992. Its membership includes representatives of the BDA and DH (and the health departments for Scotland, Wales and Northern Ireland), medical and nursing health professionals and NHS healthcare purchasers and providers, and patient representatives.
6. Its terms of reference are:
 - i. To advise the Department of Health and the BDA on which aspects of the St Vincent recommendations need to be addressed in England and their relative priority.
 - ii. To provide detailed advice on the action needed to implement those priority areas agreed with the Department following advice given at (i).
7. The work of the Task Force is progressing and it is hoped that advice will be available for issue to the health service later in 1994.

Chronic Disease Management Programme

8. Since the new arrangements for health promotion under the GP contract came into effect

in July 1993, almost 90 per cent of GPs have been approved to run chronic disease management programmes for diabetes. Practices taking part are expected to develop guidelines for delivery of care, taking account of relevant professional guidance and approved by the FHSA (with medical advice).

9. Participating GP practices will provide an organised programme for the care of patients with diabetes and are required:

- To have and maintain a register of all patients with diabetes;
- To ensure that systematic call and recall of patients on this register is taking place, either in a hospital or general practice setting;
- To ensure that all newly diagnosed patients with diabetes (or their carers when appropriate) receive appropriate education and advice on management of, and prevention of secondary complications of, their diabetes;
- To prepare with the patient an individual management plan;
- To undertake regular review at least annually of the patient including checks for potential complications and a review of the patient's own monitoring records;
- Any health professionals involved in the care of patients in the programme should be appropriately trained in the management of diabetes;
- To refer patients to other services as required and to any relevant local support agencies;
- To maintain adequate records of the performance and result of the above procedures, incorporating information from other local providers involved in the care of patients, as appropriate;
- To carry out clinical audit of the care of patients with diabetes according to the above criteria.

10. As well as benefitting individual patients information from the registers will eventually show both the incidence and prevalence of diabetes in the United Kingdom.

Clinical guidelines

11. The NHS Executive (England) is working with the professions in identifying and developing good quality clinical guidelines for commendation to purchasing health authorities and fundholding GPs to use during the contracting process with hospitals and other service providers. As a first step the NHS Executive has commended a small number of existing guidelines for pilot use this year including the British Diabetic Association's "Recommendations for the Management of Diabetes in Primary Care".

Health Care Needs Assessment

12. As part of their function health authorities are required to assess the health care needs of their populations. To help them in this task the NHS Executive commissioned a series of epidemiologically based needs assessment reviews including one on diabetes (written by Professor

Rhys Williams, a member of the CSAG diabetes committee and also a member of the DH/BDA joint taskforce). The series was published in March 1994.

CSAG report

Standards of diabetes care

13. In order to assess standards of care the CSAG first compiled a “Standards Document” “A consensus on recommendations for standards of diabetes care” drawn from a number of existing sources. Services in 11 localities (ie Districts in England and Wales and their equivalent in Scotland and Northern Ireland) were assessed against these recommendations.

14. CSAG states (paragraph 1.8) that “Standards of provision of care were found to be very variable. All the districts met some standards, several met the majority and one nearly all. The precise level of unmet need could not be established but is clearly considerable in many districts.” The report acknowledges that the sample was far from comprehensive and suggested that the figures in the report should be used in an indicative fashion.

15. Chapter 3 of the Report enlarges on this general finding by reference to the seven main points in the consensus on recommendations. There is much in this chapter to provoke thought and debate among purchasing health authorities and hospital and other service providers.

Impact of the NHS reforms

16. The report states (paragraph 1.10) “We found no evidence that the recent NHS changes had influenced the outcome of care one way or the other but, in many cases, changes in the pattern of care consequent on these NHS changes have yet to occur.”

17. We note this finding and would comment that our aim, as illustrated by the initiatives which are outlined above, is that services for people for diabetes should improve.

18. Chapter 4 of the report discusses the impact of the reforms in more detail and points both to what has been achieved, and is possible, and what still has to be achieved. The comment from 3 localities that the introduction of the purchaser and provider roles had forced purchasers and providers to focus on local needs and the best ways of meeting them appears to be supportive. To the extent that the reported lack of enthusiasm among the purchasing teams in 5 localities towards involvement in diabetes care was caused by complexities in the contracting process we would hope enthusiasm will grow as these complexities are mastered.

19. The comment in paragraph 4.3 that dialogue in some areas was inhibited by an attitude that there should be no direct communication between providers and purchasers is interesting in that this attitude is directly contrary to what we believe should be happening. The NHS Executive has, through guidance over the last 18 months, emphasised the need for purchasers and providers to work more closely together and would strongly discourage the approach and attitude described. Guidance has included EL(92)79 – Guidance for the 1993/94 Contracting Cycle; EL(93)10 – Managing Activity and Change through Contracting; EL(93)103 – Good Practice and Innovation in Contracting; and the Minister for Health’s trilogy of speeches published as Purchasing For Health – A Framework For Action.

20. We hope that “the apparent lack of a clear perspective by some of the purchasing teams of the needs of people with diabetes” is being addressed by the four initiatives outlined above and by dissemination of CSAG’s own report.

21. The choice of contract (paragraphs 4.6 and 4.7) is a matter for the local purchaser and provider. The NHS Executive, with the development of “Costing for Contracting” and the ability to focus on specialties, is to encourage the greater use of specialty contracts, and in some cases sub-specialty contracts, in preference to whole-hospital or unit contracts. Contracts serving care groups crossing a range of providers have been developed without the need to resort to elaborate/complex cross-charging arrangements. The components offered by each provider need to be clearly understood and their interdependence also understood.

22. We disagree with the view attributed to purchasers in paragraph 4.9. It is not up to providers solely to specify and monitor outcomes; quality is a joint responsibility for both purchasers and providers.

23. The 90 per cent participation by GPs in the Chronic Disease Management Disease Programme suggests that earlier worries about funding expressed to the CSAG were unfounded.

CSAG Recommendations

24. Our comments on the CSAG’s recommendations, in Chapter 5 of the report, are as follows:

1. That the UK Health Departments should encourage purchasers to ensure the adequate provision of diabetes services; and to adopt appropriate standards for the provision of these services within the contracting process.

We agree and are already making substantial progress.

2. That purchasers should establish local planning groups, involving those with expertise from both the primary and secondary sectors, to obtain the skills and knowledge needed so that the purchasing process can achieve and maintain these standards.

We agree that the contracting process should involve discussion between purchasing authorities and the provider services though we would not wish to impose a particular planning model. The guidance referred to in paragraph 19 above is relevant.

3. That comprehensive diabetes registers should be developed and maintained to assist in the assessment of local needs, in ensuring comprehensive continuing care and in monitoring quality of care.

Paragraph 3.24 of the report comments that in none of the districts visited in 1992/93 had a comprehensive population based register been established, there being no incentive to supply the necessary details by general practices not engaged in structured diabetes care. Since then, as noted above, the Chronic Disease Management Programme has been established and this requires that registers be established and maintained by GPs.

4. That purchasers should ensure that the various components of diabetes care provided by different units or trusts are specified within relevant contracts and co-ordinated through the local planning group.

We support the general principles expressed in this recommendation though it is for local purchasers and providers to determine the nature and structure of their contracts.

5. That standards for continuing diabetes outpatient care should be specified separately within contracts in order to ensure appropriate performance and monitoring.

We note this recommendation which, we understand, flows from CSAG's belief that, while quality standards (and their specification in contracts) are no more important for out-patient services than for in-patient services, they are more easily specified at present. The suggestion is therefore that purchasers and providers should start with these.

6. That, where purchasers lack the necessary expertise to implement, to an adequate level, the recommendations set out above, outside expertise should be brought in and that the Joint British Diabetic Association/Department of Health St Vincent Task Force for Diabetes should be asked to identify appropriate mechanisms for this to take place.

It is for purchasers to assess to what extent they might need to bring in outside expertise and it open to them to do so. The UK Health Departments would be happy to consider any problems brought to their attention by purchasers or CSAG.

7. That those working in secondary care should be encouraged to continue to develop their role in supporting the optimum provision of care in the primary care sector.

Helpful co-operation between secondary and primary care providers is always to be encouraged.

8. That each local planning group should consult with one or more relevant consumer groups so that consumers can be given greater involvement in the development of their diabetes services.

We agree that the views of patients should inform the planning process.

9. That, as continuing education of all professionals concerned with the care of people with diabetes is essential for the maintenance of standards, the need for this should be recognised in contracts.

The contract price should include all that is necessary for the service to be delivered to the right standard, including continuing education.

10. That, while many supportive services for the treatment of diabetic complications need to be strengthened and maintained, services for the surveillance and treatment of diabetic eye disease, in particular, should be improved, and consideration given to the organisation of retinal screening programmes, and enhancement of the provision and development of retinopathy treatment services (including laser photocoagulation, angiography and retinal photography).

We have asked that this be considered carefully by the Joint St Vincent Task Force whose remit includes drawing up advice on the prevention and treatment of complications associated with diabetes.

11. That a further examination of diabetes services should be undertaken in approximately two years' time, when the effects of the contracting process should be expected to be more evident.

We note this recommendation.

The St Vincent Declaration

To promote:

- detection and control of diabetes and its complications incorporating self-care and community support
- awareness among public, patients and health care professionals of present opportunities and future potential for prevention of diabetic complications, ultimately of diabetes itself
- specialised paediatric care for children with diabetes and social, economic and emotional support for their families
- reinforcement of existing centres of excellence for diabetes care, education and research and creation of new ones
- independence, equity and self-sufficiency for all people with diabetes – children, adolescents, adults and the elderly
- fullest possible integration of the diabetic citizen into society and resistance to prejudice and ignorance about diabetes
- prevention of severe diabetic complications by ensuring better use of measures currently known to be effective, thereby:
 - reducing new blindness due to diabetes by one third or more
 - reducing numbers of people entering end stage diabetic renal failure by at least one third
 - reducing by one half the rate of limb amputations for diabetic gangrene
 - cutting morbidity and mortality from coronary heart disease in the diabetic by vigorous programmes of risk factor reduction
 - achieving pregnancy outcome in the diabetic woman that approximates that of the non-diabetic woman
- establishment of modern information technology systems to monitor the quality of the health care provided for diabetes and the validity of laboratory and technical procedures used in diagnosis and self-management
- collaboration in diabetes research and development in Europe and internationally, through appropriate agencies and in partnership with national diabetes patient organisations
- creation of joint machinery between WHO and IDF [International Diabetes Federation], European Region to bring these recommendations to fruition.

1989

CIRCULATION LIST

BRITISH DIABETIC ASSOCIATION RESPONSE TO CSAG REPORT

British Diabetic Association Staff

British Diabetic Association Regional Offices

British Diabetic Association Trustees and Members of all Committees

British Diabetic Association Area Coordinators

Consultant Diabetologists

Diabetes Specialist Nurses

Directors of Public Health

Chief Executives of Family Health Service Authorities

Chief Executives of National Health Service Trusts/Health Authorities/Boards

Directors of Purchasing/Planning

Welsh Office

Scottish Home & Health Department

Department of Health and Social Security in Northern Ireland

Members of St Vincent Task Force

Dr Ann Dawson

Prof David Shaw

Dr Leslie Bissett

Tom Mead

REPORT OF THE CLINICAL STANDARDS ADVISORY GROUP - DIABETES

THE BRITISH DIABETIC ASSOCIATION'S RESPONSE

Implications of the diabetes report of the Clinical Standards Advisory Group, and the Government's Response to that Report

Cornerstones of an Adequate Standard of Diabetes Care

It is critically important that the case is made, as a matter of urgency, for the adequate funding of high quality care for people with diabetes because the 'purchasing round' for health services for 1995/6 is now in its consultation stage. This means vigorous representations to the health authorities and General Practice consortia who hold or influence the budgetary allocations, to make them aware of the high priority which the British Diabetic Association (BDA) and Government place on improved diabetes care.

The Clinical Standards Advisory Group diabetes report contains recommendations for diabetes care which if implemented will provide the high quality care which the BDA is trying to achieve.

INTRODUCTION

The Clinical Standards Advisory Group (CSAG) was established in 1991 to advise UK Health Ministers. Its second report, published this summer, addresses standards of care for people with diabetes throughout the UK. The report includes the Government's response to the expert group's recommendations and a summary of published consensus standards for diabetes care.

As the report notes, diabetes accounts for a very significant proportion of ill-health in the UK, costing about 5% of the UK NHS budget. The 1.5-2.0 % of people with diabetes require around three times the health care resources of the general population, much related to preventable complications of diabetes. The lifetime expectancy of diabetes is around 10%, about two-thirds will die from diabetes-associated cardiovascular disease, 10-15% risk blindness, 5-10% amputation and 10% renal failure.

The British Diabetic Association (BDA), with over 135 000 members, is greatly concerned with improving patient care, and in particular with the prevention of complications and maintenance of quality of life. The BDA for the most part endorses the standards, findings and recommendations of the CSAG diabetes report, and in addition the Government's response to this. All interested parties agree that this is a report of significance.

The Department of Health and the BDA are already working together in a Joint Task Force on diabetes care, set up to make recommendations on the implementation of the St Vincent Declaration, and the applicability of its targets for the outcome of diabetes care in the UK. The Task Force is taking account of the CSAG-diabetes report in preparing its own advice to Health Ministers on the provision of diabetes care.

In this paper the BDA seeks to highlight those recommendations made by the CSAG which are of the highest priority to its members. The general tone of the report recognises and endorses the patient-centred nature of diabetes care (see for example p. 15, section 5.1, and p. 16, section 5.3). The report accepts the important role of patients and carers in the development and specification of diabetes health care (p. 11, recommendation 8), in addition to the now well accepted concepts of patient self-management and self-sufficiency.

The BDA also strongly support the last recommendation (p. 11, recommendation 11) for repeated examinations of diabetes care provision in the future and sees this evaluation and improvement as a routine part of UK diabetes care, with which they are willing to assist.

Areas of Diabetes Care Highlighted by the CSAG-Diabetes Recommendations

1. Local Diabetes Service Advisory Groups

Recommendation 2 (p. 11) states that "... purchasers should establish local planning groups .. ", and recommendation 8 (p. 11) that "...each local planning group should consult with one or more relevant consumer groups..". The Government response endorses these recommendations in principle (p. 38-39). Such groups are coming to be known as 'local diabetes service advisory groups' (LDSAGs), and can have a valuable input into the needs -> standards -> policy -> planning -> contracts -> monitoring process.

The BDA believes that such groups are an essential feature of the provision of diabetes care in all localities, and that they must be multidisciplinary and include patients. The Association is concerned to note the existence of policies and contracts developed without specialist or patient input, contrary to directives of Professional bodies, the NHS Executive and the CSAG report. Further information on the constitution of local diabetes service advisory groups, and the different models established in various parts of the UK, is available from the BDA on request.

2. Diabetes Registers

"Comprehensive registers should be developed and maintained.." (p.11, recommendation 3). The Government's response (p.38) makes it clear that it regards these as an integral part of diabetes management programmes in primary health care, in keeping with the BDA's view that registers should be population based.

The St Vincent Declaration and the NHS Diabetes Research and Development Review have endorsed the importance of information technology to improved diabetes care. The BDA and Department of health have already co-operated in the funding of the development of the UK Recommended Dataset, and in the provision by the BDA of the specialist clinical advice to the Family Health Service Computer Unit's diabetes software initiative.

Diabetes registers generally contain considerable amounts of clinical data, related to risk factors, complications and the like, and are therefore important tools in needs assessment in prompting for continuing care and complications surveillance, and in the monitoring of care quality. The BDA endorses Recommendation 5 (p.11) in suggesting that standards for diabetes care should be separately specified within contracts, is thus supported by the implementation of registers which can be used to monitor contract performance. It also endorses Recommendation 1(P.11) that UK Health Departments should encourage purchasers to contract for appropriate provision and standards of services for diabetes.

3. Integrated care

The Report says that the best care for patients is provided where primary and specialist services work together. Recommendation 2(p.11) recognizes the importance of input from both primary and secondary sectors in the deployment of skills to achieve the appropriate standards of care. Recommendation 7 notes that the optimum provision of care in the primary sector requires support from those working in the secondary sector. The Government's response (p 38-39) adds support to these

remarks. An important element of this arises from concern with the finding of the CSAG-diabetes group (p 9, section 4.7) that fragmentation of care was occurring in some localities through contracts for support services being placed with different trusts. Recommendation 4 (p.11), whose general principles are endorsed by the Government's response (p. 39), seeks to ensure that all components are appropriately specified, and that the local planning groups ensure their provision and co-ordination.

The BDA recognizes that primary health care plays a major role in providing an adequate standard of care for people with diabetes, and notes that most patients will require help from the secondary sector for varying lengths of time during the course of their condition. As a result the best quality care will be provided by a service shared between primary and secondary care, and based on the individual needs of the patient and depend on the availability of skills, resources and interest. This underlines CSAG-diabetes view that the standard of care necessarily provided for the individual should be independent of the site of care (p. 13 section 1e), but these standards can only be maintained in either sector with full provision of support services, and appropriate monitoring of the process and outcomes of care (p. 18-20, section 7). Shared care can be facilitated by the further development of Diabetes Centres.

4. Professional education

The CSAG-diabetes report, states that all professionals in both primary and secondary sector teams should be released and funded for continuing education (p.20, section 8.1). Non-medically qualified professionals were found not to be adequately helped (p.6 section 3.6). The BDA recognising the special role that nurses, dieticians and chiropodists play in the education and support of people with diabetes, agrees with this and also endorses recommendation 9 (p. 11), that this need should be recognised in contracts. The Government accepts this and notes that "The contract price should include all that is necessary., including continuing education".

5. Complications of Diabetes

Much of the personal and economic costs of diabetes result from its complications. As noted by the St Vincent Declaration, these are potentially preventable (see also p.16, section 5.4). For example systems for retinal screening must be established (p.11, recommendation 10). This is consistent with statements in the BDA patient document "What diabetic care to expect". Registers for the support of "Continuing Care" (p. 11, recommendation 3) are also relevant here. The CSAG-diabetes was also concerned that diagnostic ophthalmological retinal assessment and prompt treatment facilities were adequately provided (p. 11, recommendation 10).

Appropriate facilities must be similarly specified for the prevention, surveillance, and treatment and support for foot, renal and cardiovascular complications, and the special needs of pregnancy. We note that these issues are addressed within the consensus on standards (Appendix 1, p.25-29).

The BDA, whilst recognising the importance of hyperglycaemia in avoiding long term complications, would like to emphasise, in the light of discussions on the Diabetes Control and Complications Trial (DCCT), the importance of minimising the risk of hypoglycaemia.

6. Purchasing

Purchasers repeatedly commented to the CSAG-diabetes visitors on their lack of the skills necessary to specify an monitor diabetes care (p.10, section 4.9). This leads to recommendation 6 (import of expertise) (p. 11), which the Government endorsed for those purchasers who recognize the problem (p.39).

The Association remains concerned that some purchasers do not recognize their problem, others choose not to recognize it, and others do not know where to turn for appropriate advice. The BDA through its professional network has always been available to provide advice. It is hoped that managers and chief executives of provider units and commissioning authorities will make full use of this expertise. the BDA is also in the process of establishing regional networks which will be able to provide assistance.

7. Other issues

- i) The BDA regrets that there is little reference in the CSAG report to the care for young people with diabetes. The Joint BDA/DH Task Force has received a report from the Advisory Subgroup, which it set up to look at the special requirement of children and young people, and the Task Force will be making recommendations for these services. The BDA recommends that each District should have a Paediatric Diabetes team led by the Consultant Paediatrician with a special interest in Diabetes and including a Paediatric specialist nurse.
- ii) The BDA considers that when developing standards for diabetes services, providers include the facility to respond to individual patient choice and any nationally agreed guidelines or standards must be flexible and allow the provision of care, tailored to the wishes and circumstances of the individual.

CONCLUSIONS

The CSAG-diabetes report together with the Government response offers a number of very useful recommendations, which should ensure an adequate standard of care in diabetes throughout the UK. As a patient association the BDA exhorts those responsible for the commissioning and provision of diabetes care to adopt and develop the recommendations, and to seek the Association's help and advice in obtaining any expert support that might be necessary. It also urges its members, patients, professional and others concerned with diabetes care, to bring this valuable report to the attention of the commissioners and providers of diabetes care.

Source document

Clinical Standards Advisory Group. Standards of clinical care for people with diabetes. London: HMSO, 1994.

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The British Diabetic Association (BDA), with over 135 000 members, is greatly concerned with improving patient care, and in particular with the prevention of complications and maintenance of quality of life. The BDA for the most part endorses the standards, findings and recommendations of the CSAG diabetes report, and in addition the Government's response to this. All interested parties agree that this is a report of significance.

The Department of Health and the BDA are already working together in a Joint Task Force on diabetes care, set up to make recommendations on the implementation of the St Vincent Declaration, and the applicability of its targets for the outcome of diabetes care in the UK. The Task Force is taking account of the CSAG-diabetes report in preparing its own advice to Health Ministers on the provision of diabetes care.

In this paper the BDA seeks to highlight those recommendations made by the CSAG which are of the highest priority to its members. The general tone of the report recognises and endorses the patient-centred nature of diabetes care (see for example p. 15, section 5.1, and p. 16, section 5.3). The report accepts the important role of patients and carers in the development and specification of diabetes health care (p. 11, recommendation 8), in addition to the now well accepted concepts of patient self-management and self-sufficiency.

The BDA also strongly support the last recommendation (p. 11, recommendation 11) for repeated examinations of diabetes care provision in the future and sees this evaluation and improvement as a routine part of UK diabetes care, with which they are willing to assist.

Areas of Diabetes Care Highlighted by the CSAG-Diabetes Recommendations

1. Local Diabetes Service Advisory Groups

Recommendation 2 (p. 11) states that ".. purchasers should establish local planning groups .. ", and recommendation 8 (p. 11) that "..each local planning group should consult with one or more relevant consumer groups..". The Government response endorses these recommendations in principle (p. 38-39). Such groups are coming to be known as 'local diabetes service advisory groups' (LDSAGs), and can have a valuable input into the needs -> standards -> policy -> planning -> contracts -> monitoring process.

The BDA believes that such groups are an essential feature of the provision of diabetes care in all localities, and that they must be multidisciplinary and include patients. The Association is concerned to note the existence of policies and contracts developed without specialist or patient input, contrary to directives of Professional bodies, the NHS Executive and the CSAG report. Further information on the constitution of local diabetes service advisory groups, and the different models established in various parts of the UK, is available from the BDA on request.

2. Diabetes Registers

"Comprehensive registers should be developed and maintained.." (p.11, recommendation 3). The Government's response (p.38) makes it clear that it regards these as an integral part of diabetes management programmes in primary health care, in keeping with the BDA's view that registers should be population based.

The St Vincent Declaration and the NHS Diabetes Research and Development Review have endorsed the importance of information technology to improved diabetes care. The BDA and Department of health have already co-operated in the funding of the development of the UK Recommended Dataset, and in the provision by the BDA of the specialist clinical advice to the Family Health Service Computer Unit's diabetes software initiative.

Diabetes registers generally contain considerable amounts of clinical data, related to risk factors, complications and the like, and are therefore important tools in needs assessment in prompting for continuing care and complications surveillance, and in the monitoring of care quality. The BDA endorses Recommendation 5 (p.11) in suggesting that standards for diabetes care should be separately specified within contracts, is thus supported by the implementation of registers which can be used to monitor contract performance. It also endorses Recommendation 1(P.11) that UK Health Departments should encourage purchasers to contract for appropriate provision and standards of services for diabetes.

3. Integrated care

The Report says that the best care for patients is provided where primary and specialist services work together. Recommendation 2(p.11) recognizes the importance of input from both primary and secondary sectors in the deployment of skills to achieve the appropriate standards of care. Recommendation 7 notes that the optimum provision of care in the primary sector requires support from those working in the secondary sector. The Government's response (p 38-39) adds support to these

remarks. An important element of this arises from concern with the finding of the CSAG-diabetes group (p 9, section 4.7) that fragmentation of care was occurring in some localities through contracts for support services being placed with different trusts. Recommendation 4 (p.11), whose general principles are endorsed by the Government's response (p. 39), seeks to ensure that all components are appropriately specified, and that the local planning groups ensure their provision and co-ordination.

The BDA recognizes that primary health care plays a major role in providing an adequate standard of care for people with diabetes, and notes that most patients will require help from the secondary sector for varying lengths of time during the course of their condition. As a result the best quality care will be provided by a service shared between primary and secondary care, and based on the individual needs of the patient and depend on the availability of skills, resources and interest. This underlines CSAG-diabetes view that the standard of care necessarily provided for the individual should be independent of the site of care (p. 13 section 1e), but these standards can only be maintained in either sector with full provision of support services, and appropriate monitoring of the process and outcomes of care (p. 18-20, section 7). Shared care can be facilitated by the further development of Diabetes Centres.

4. Professional education

The CSAG-diabetes report, states that all professionals in both primary and secondary sector teams should be released and funded for continuing education (p.20, section 8.1). Non-medically qualified professionals were found not to be adequately helped (p.6 section 3.6). The BDA recognising the special role that nurses, dieticians and chiropodists play in the education and support of people with diabetes, agrees with this and also endorses recommendation 9 (p. 11), that this need should be recognised in contracts. The Government accepts this and notes that "The contract price should include all that is necessary, including continuing education".

5. Complications of Diabetes

Much of the personal and economic costs of diabetes result from its complications. As noted by the St Vincent Declaration, these are potentially preventable (see also p.16, section 5.4). For example systems for retinal screening must be established (p.11, recommendation 10). This is consistent with statements in the BDA patient document "What diabetic care to expect". Registers for the support of "Continuing Care" (p. 11, recommendation 3) are also relevant here. The CSAG-diabetes was also concerned that diagnostic ophthalmological retinal assessment and prompt treatment facilities were adequately provided (p. 11, recommendation 10).

Appropriate facilities must be similarly specified for the prevention, surveillance, and treatment and support for foot, renal and cardiovascular complications, and the special needs of pregnancy. We note that these issues are addressed within the consensus on standards (Appendix 1, p.25-29).

The BDA, whilst recognising the importance of hyperglycaemia in avoiding long term complications, would like to emphasise, in the light of discussions on the Diabetes Control and Complications Trial (DCCT), the importance of minimising the risk of hypoglycaemia.

6. Purchasing

Purchasers repeatedly commented to the CSAG-diabetes visitors on their lack of the skills necessary to specify an monitor diabetes care (p.10, section 4.9). This leads to recommendation 6 (import of expertise) (p. 11), which the Government endorsed for those purchasers who recognize the problem (p.39).

The Association remains concerned that some purchasers do not recognize their problem, others choose not to recognize it, and others do not know where to turn for appropriate advice. The BDA through its professional network has always been available to provide advice. It is hoped that managers and chief executives of provider units and commissioning authorities will make full use of this expertise. The BDA is also in the process of establishing regional networks which will be able to provide assistance.

7. Other issues

- i) The BDA regrets that there is little reference in the CSAG report to the care for young people with diabetes. The Joint BDA/DH Task Force has received a report from the Advisory Subgroup, which it set up to look at the special requirement of children and young people, and the Task Force will be making recommendations for these services. The BDA recommends that each District should have a Paediatric Diabetes team led by the Consultant Paediatrician with a special interest in Diabetes and including a Paediatric specialist nurse.
- ii) The BDA considers that when developing standards for diabetes services, providers include the facility to respond to individual patient choice and any nationally agreed guidelines or standards must be flexible and allow the provision of care, tailored to the wishes and circumstances of the individual.

CONCLUSIONS

The CSAG-diabetes report together with the Government response offers a number of very useful recommendations, which should ensure an adequate standard of care in diabetes throughout the UK. As a patient association the BDA exhorts those responsible for the commissioning and provision of diabetes care to adopt and develop the recommendations, and to seek the Association's help and advice in obtaining any expert support that might be necessary. It also urges its members, patients, professional and others concerned with diabetes care, to bring this valuable report to the attention of the commissioners and providers of diabetes care.

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